Let's Get Movin'!
Expanding the "how to" in your toolbox to make activity and participation meaningful and feasible

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Intro to Activity and Participation

Diagram:

- "Health Condition" (disorder or disease)
  - Body Functions and Structures
  - Activities
  - Participation
    - Personal Factors
    - Environmental Factors
Considerations for individuals with Down syndrome\textsuperscript{1,2}:

- Hypotonia (Low Muscle Tone)
- Increased joint mobility and ligamentous laxity
- Linear growth differences
- Decreased strength
- Decreased coordination
- Associated medical complexities

Body Functions & Structures

- Motivation
- Cognitive skills
- Learning style
- Communication

Personal Factors
<table>
<thead>
<tr>
<th><strong>Barriers</strong></th>
<th><strong>Facilitators</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Lack of accessible, inclusive, and properly designed programs</td>
<td>- Knowledge of physical activity and health</td>
</tr>
<tr>
<td>- Transportation</td>
<td>- Positive attitude with exercise</td>
</tr>
<tr>
<td>- Negative attitudes or challenging behaviors</td>
<td>- Determination</td>
</tr>
<tr>
<td>- Competing family obligations</td>
<td>- Positive social and family attitudes</td>
</tr>
<tr>
<td>- Parental education and income</td>
<td>- Knowledgeable professionals</td>
</tr>
<tr>
<td>- Lack of social support</td>
<td>- Structured programs</td>
</tr>
<tr>
<td></td>
<td>- Adapted to needs</td>
</tr>
<tr>
<td></td>
<td>- Provide knowledge</td>
</tr>
<tr>
<td></td>
<td>- Are inclusive</td>
</tr>
<tr>
<td></td>
<td>- Promote social interaction</td>
</tr>
<tr>
<td></td>
<td>- Promote enjoyment</td>
</tr>
</tbody>
</table>
Expanding the “HOW TO” in your Toolbox

PHYSICAL ACTIVITY
What is Physical Activity

Bodily movement produced by the contraction of skeletal muscle that increases energy expenditure above a baseline level

Aerobic
Muscle Strength
Bone Strength
Balance
Flexibility
Physical Activity Guidelines for Americans³

Preschool Aged Children: 3-5 years old
- Physically activity throughout
- Active play
- **Variety**

Children and Adolescents: 6-17 years old
- 60 minutes (1 hour) or more of **moderate-to-vigorous** physical activity daily
  - Aerobic: Vigorous-intensity physical activity
  - Muscle-strengthening
  - Bone-strengthening

***Children with disabilities may need to modify these recommendations based on type of disability and overall conditioning level***
How to Determine Intensity:

<table>
<thead>
<tr>
<th></th>
<th>How Hard Am I working?</th>
<th>Intensity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>This feels very relaxed!</td>
<td>Very Light Activity</td>
</tr>
<tr>
<td>2</td>
<td>I can do this all day long.</td>
<td>Light Activity</td>
</tr>
<tr>
<td>3</td>
<td>I am still fairly relaxed but breathing a little harder. I can still talk easily.</td>
<td>Light Activity</td>
</tr>
<tr>
<td>4</td>
<td>I am just breaking a sweat, but I can still talk comfortably.</td>
<td>Moderate Activity</td>
</tr>
<tr>
<td>5</td>
<td>I am sweating more, and getting a little uncomfortable but can still talk fairly well.</td>
<td>Moderate Activity</td>
</tr>
<tr>
<td>6</td>
<td>I can still talk, but it is getting harder to breathe. I am sweating much more.</td>
<td>Moderate Activity</td>
</tr>
<tr>
<td>7</td>
<td>I can still talk, but it is hard. I am sweating a lot!</td>
<td>Vigorous Activity</td>
</tr>
<tr>
<td>8</td>
<td>I can speak very short sentences. I am uncomfortable but can keep going a little longer!</td>
<td>Vigorous Activity</td>
</tr>
<tr>
<td>9</td>
<td>I cannot respond to your questions. I am uncomfortable.</td>
<td>Very Hard Activity</td>
</tr>
<tr>
<td>10</td>
<td>I can’t keep up, I am all out of breath and need to stop!</td>
<td>Maximum Effort</td>
</tr>
</tbody>
</table>
Prior to beginning any new fitness, physical activity, exercise routine, consider checking in with your primary care provider, a physician, and/or physical and occupational therapists.
Physical Activity at Home
Ideas to implement physical activity at home\textsuperscript{4,5}

- **Implement it into a daily routine**
  - Create a schedule and routine with a visual (include a motivator at the end!)
    - [https://connectability.ca/visuals-engine/](https://connectability.ca/visuals-engine/)
    - Keep it consistent!
  - Create a calendar, use a dry erase board, or create a log of activities and performance

- **Start with small, reasonable goals**
  - Increase duration by seconds or minutes
  - Increase intensity for short periods of time
  - Increase distance traveled
    - Use an accelerometer or fitness watch to track goals
Home ideas cont.

- **Use exercise videos**
  - Pre-existing videos for kids (start with beginner or easy)
  - Make your own! And then complete them together with family members or friends
  - Use motivating music

- **Make games out of exercises**
  - Involve the whole family
  - Friendly competition
  - Bucket game, existing games including Twister or Hyperdash, Fitivities, The Floor is Lava, create rules within games
<table>
<thead>
<tr>
<th>Balance (including Proprioception and Postural Control)</th>
<th>Core (including Core Strength and Core Stability)</th>
<th>Coordination (including Bilateral and Hand-Eye Coordination)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Balance</strong> allows us to hold our body up without falling over</td>
<td><strong>Core Strength</strong> involves the ability of the abdominal, back and hip muscles to work together</td>
<td><strong>Coordination</strong> involves use of the arms or legs together</td>
</tr>
<tr>
<td><strong>Proprioception</strong> is our sense of where our body is in space</td>
<td><strong>Core Stability</strong> involves the ability of our spine to remain intact and support movement without collapsing</td>
<td><strong>Bilateral Coordination</strong> involves using both sides of the body simultaneously or reciprocally</td>
</tr>
<tr>
<td><strong>Postural Control</strong> involves alignment of the head, neck and trunk while moving arms and legs</td>
<td></td>
<td><strong>Hand-Eye Coordination</strong> involves use of our vision and muscles together</td>
</tr>
</tbody>
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Balance (including Proprioception and Postural Control)

**Balance** allows us to hold our body up without falling over

**Proprioception** is our sense of where our body is in space

**Postural Control** involves alignment of the head, neck and trunk while moving arms and legs

<table>
<thead>
<tr>
<th>Activity Cards</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Balance:</strong></td>
</tr>
<tr>
<td><strong>Tree Pose Series</strong></td>
</tr>
<tr>
<td>(Items needed: Pillow)</td>
</tr>
<tr>
<td>(Perform each for 10-60 seconds)</td>
</tr>
<tr>
<td>- Feet together arms across chest-eyes open</td>
</tr>
<tr>
<td>- Feet together arms across chest-eyes closed</td>
</tr>
<tr>
<td>- Feet together standing on pillow arms across chest-eyes open</td>
</tr>
<tr>
<td>- Feet together standing on pillow arms across chest-eyes closed</td>
</tr>
<tr>
<td><strong>Tightrope Series</strong></td>
</tr>
<tr>
<td>(Set up: Mark 2 spots ~10-20 feet apart with a line between the points)</td>
</tr>
<tr>
<td>- Walking forward heel toe pattern on a line</td>
</tr>
<tr>
<td>- Walking backward heel toe pattern on a line</td>
</tr>
<tr>
<td>- Walking sideways on a line</td>
</tr>
<tr>
<td><strong>Flamingo Pose Series</strong></td>
</tr>
<tr>
<td>(Perform each for 10-60 seconds)</td>
</tr>
<tr>
<td>- Standing on 1 leg with 1 leg on a step</td>
</tr>
<tr>
<td>- Standing on 1 leg with 1 leg on a ball</td>
</tr>
<tr>
<td>- Standing on 1 leg</td>
</tr>
<tr>
<td><strong>Pillow Series</strong></td>
</tr>
<tr>
<td>(Items needed: Pillow)</td>
</tr>
<tr>
<td>(Perform each for 10-60 seconds)</td>
</tr>
<tr>
<td>- Stand on Pillow with feet together and squat down to touch ground, stand up and reach arms overhead</td>
</tr>
<tr>
<td>- Stand on Pillow with feet together and march in place</td>
</tr>
<tr>
<td>- Step onto pillow forward, and off of pillow backwards</td>
</tr>
<tr>
<td><strong>Animal Yoga Series</strong></td>
</tr>
<tr>
<td>(Perform each for 10-60 seconds)</td>
</tr>
<tr>
<td>- Hold an Animal Yoga Pose</td>
</tr>
<tr>
<td>Examples:</td>
</tr>
<tr>
<td>- Flamingo</td>
</tr>
<tr>
<td>- Dog</td>
</tr>
<tr>
<td>- Cat</td>
</tr>
<tr>
<td>- Giraffe</td>
</tr>
</tbody>
</table>
- **Core Strength** involves the ability of the abdominal, back and hip muscles to work together

- **Core Stability** involves the ability of our spine to remain intact and support movement without collapsing

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**ACTIVITY CARDS**

**Core:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Instructions</th>
</tr>
</thead>
</table>
| Super Kid Series  | • Lay on your tummy and lift arms out straight in front of you  
                   | • Lay on your tummy and lift legs out straight behind you  
                   | • Lay on your tummy and lift both arms and legs out straight |
| Bridge Series     | • Lay on your back with your knees bent and lift your bottom up and lower slowly  
                   | • Lay on your back with your knees bent and lift your bottom up and hold  
                   | • Lay on your back with your knees bent and lift your bottom up and march your legs up/down slowly |
| Ball Toss         | • Obtain ½ kneeling position and toss a ball back and forth between you and your partner  
                   | • Repeat with the other knee up |
| Tap Dance Series  | • Stand behind a stool or the bottom step and alternate tapping with each foot  
                   | • Stand behind a stool or the bottom step and step up onto the step and then back down  
                   | • Stand to the side of the stool or the bottom step and step up onto the step and then back down |
| Sit to Stand Series | • Stand in front of a chair, sit down slowly, and stand back up  
                       | • Stand in front of a chair, sit down slowly, stand back up and jump  
                       | • Stand in front of a chair, sit down slowly, stand back up, and perform 4 standing marches |
Coordination (including Bilateral and Hand-Eye Coordination)

- Coordination involves use of the arms or legs together
- Bilateral Coordination involves using both sides of the body simultaneously or reciprocally
- Hand-Eye Coordination involves use of our vision and muscles together

**ACTIVITY CARDS**

**Coordination:**

<table>
<thead>
<tr>
<th>Activity Series</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jumping Jacks Series</td>
<td>Jumping Jacks Slowly in Place, Jumping Jacks Pattern moving forward, Jumping Jacks pattern moving backward</td>
</tr>
<tr>
<td>Galloping Series</td>
<td>Gallop forward from 1 point to another and back, Repeat with the other leg leading</td>
</tr>
<tr>
<td>March Series</td>
<td>March in place with arms at hips, March in place while bringing your arms up and down, March forward with arms at hips, March forward while bringing your arms up and down</td>
</tr>
<tr>
<td>Jump Rope Series</td>
<td>Jump forward over the line, turn around and repeat, Jump Sideways back and forth over the line, Jump forward, then backward over the line, Frog jump (bend way down to touch the ground, leap in the air with arms overhead) back and forth over the line</td>
</tr>
<tr>
<td>Bear Series</td>
<td>Bear walk from 1 point to another and back, Bear walk around obstacles from 1 point to another and back, Bear Run!</td>
</tr>
</tbody>
</table>
Exercise Buckets—Pick 1 exercise in each

Balance

Tree Pose Series
(Items needed: Pillow)
(Perform each for 10-60 seconds)

Core

Sit to Stand Series
(Perform each for 10-60 seconds)

Coordination

Jumping Jacks Series
(Set up: Mark 2 spots ~10-20 feet apart)
(Perform each for 10-60 seconds)
Physical Activity in the Community
How to incorporate physical activity in the community

● Utilize support people to complete exercises
  ○ Respite care providers, family members, babysitters

● Organize neighborhood or play group walks/rides/rolls
  ○ Neighborhood apps and social media pages

● Look into a gym membership for older adolescents
  ○ Utilize recumbent bikes, Zumba classes, weights, and treadmills. All with close supervision.

● Plan family bike rides to a motivating destination
  ○ Parks, sporting events, farmers market, lunch

● Explore community programs or sports programs

Home Resources:
- Exercise fact sheets from the National Center on Health, Physical Activity and Disability (NCHPAD)
  - https://www.nchpad.org/Articles/9/Exercise-and-Fitness
- Visual support generator
  - https://keenconnectivity.com/visual-engine/
- Exercise video examples
  - https://www.youtube.com/watch?v=1T8jdpJzjal
  - https://www.youtube.com/watch?v=Q0DIPnyot;
  - https://www.youtube.com/watch?v=1_A_fH1fZ1f

Community Resources:
- Special Olympics Young Athletes
  - https://www.specialolympicswisconsin.org/
- Gigi’s Playhouse: https://gigisplayhouse.org/madison/calendar/
- Some examples include: Adaptive Dance with Magnum Opus & Gigi Fit Adult
- Madison School Community Recreation
  - https://www.mcr.org/our-programs/adoptions-recreation-inclusion
- Madison Aquatic Club
  - https://www.teamunify.com/home.jsp?team=nemac_jeannakatz@gmail.com for more information
- Swim Team
  - https://www.swimwest.com/swim-levels/swimwest-swim-school-levels/
- Miracle League of Dane County
  - https://www.dane-countymiracleleague.com/
- Challenger League
  - https://www.challengerleague.org/
- Wisconsin Martial Arts and Fitness Center
  - https://www.wiscmartialarts.com/
- Superhero Martial Arts
- Fury Athletics
- YMCA Of Dane County-Adaptive
  - https://www.ymcadane.org/programs/adaptive

Disclaimer: Please note that none of the resources listed here are sponsored or endorsed by the presenters today. Participation is voluntary, leaving responsibility fully in the hands of the participants. It is also important to note that not all of the resources may be appropriate for everyone, and consultation with your PCP, PT, or OT may be helpful to determine an appropriate fit.
10-12% of children with Down syndrome have been reported to learn to ride a 2 wheeled bicycle. Benefits include improved confidence, opportunities for socialization, balance, and physical activity.

In a study that looked at teaching children with Down syndrome to ride a bicycle (Ulrich et al):

- 56% of children who participated in the training program learned to bike
- 12 months later, those who learned to ride a bike spent less time in sedentary activities (by 75 minutes/day)
- Those who learned to ride a bike spent more time in moderate to vigorous activity than the control group
Bicycling Resources

Help with learning to ride:
- iCan Bike Camp
  - June 15-19th, 2020 in Milwaukee, WI
  - https://icanshine.org/ican-bike-milwaukee-wi/
- Madison School and Community Recreation
  - Dates not yet determined
  - Guidelines for Success
    - Realistic expectations
    - Communication regarding child’s disability
    - https://www.mscr.org/our-programs/trips-special-events/learn-2-ride
- Your local Physical and Occupational Therapists

Adaptive Bikes:
- More “Local” options
  - Emerys
    - Location: Milwaukee, WI & Menomonee Falls, WI
    - Contact: 414-463-0770 for no obligation assessment
    - Website: https://www.emerys.com/about/adaptive-bicycles-for-the-differently-abled-pg106.htm
  - Project Mobility
    - Location: St. Charles, IL
    - Website: https://www.projectmobility.org/
- More “National” options
  - Freedom Concepts: https://www.freedomconcepts.com/
  - Ambus: www.ambus.org
  - Rifton: https://www.rifton.com/products/special-needs-tricycles/adaptive-tricycles

Funding Considerations:
- Insurance
  - Letter of Medical Necessity (from assistance of OT, PT)
- Grants
  - Challenged Athletes Foundation
- Organizations
  - Consider Local Organizations such as Elks, Easter Seals, Salvation Army
  - Kiwanis, Lions’, Optimists, Rotary, Knights of Columbus, Shriner’s etc
- Online Fundraising
Maximizing Success

A script for Community Partner(s):
My name is ____. My medical complexities are listed here: _____. I learn best with visual demonstration and increased time to process the directions. A visual schedule may also help me know what is coming next, or what items make up an activity. I may need to break up the activity into parts before putting it all together. I may also need a few more times to practice.
Summary and Questions
References


Image References


Slide 19: People: https://encrypted-tbn0.gstatic.com/images?q=tbn%3AANd9GcRYHq3Y-LqcoKdTgwulxxyIDNCVgzIe19NjN6Y9Xu9rW6B9dV
